443 'I am normal': young people's perspectives of CF and the influence this has on treatment adherence

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Introduction: A qualitative PhD study examining transition to adulthood for young people with CF.
Method: In-depth semi-structured interviews were conducted with 8 male and 10 female CF patients aged 16–21 years. The study has been conducted and analysed using Grounded Theory.
Results: The issue of adherence was pertinent in the lives of the young people. Participants' described themselves as being adherent, partially adherent or non-adherent. Attitudes towards and decisions about adherence were strongly influenced by their notions of normal: what it means to be normal, to lead a normal life and the perceived impact of CF upon this.
Participants in the adherent category felt that due to having never known any different, living with CF and carrying out treatments was, to them, a normal life. In contrast the non-adherent participants felt that having CF was not normal. They expressed a strong desire to be normal and lead a normal life and would go to great lengths to achieve this including non-adherence to treatments. Those who spoke of being partially adherent sought to live as normal a life as they felt was possible. They attempted to strike a balance between CF and other priorities in their lives and in doing so felt complete adherence was not possible.
Discussion: Transition to adulthood is a time of great change and health care professionals need to be aware of the competing priorities for young people with CF during this phase. Results have highlighted the need for an understanding and individualised approach to improving adherence which, takes into account the young persons perception of normality and how CF impacts upon this.

444 What do CF patients and their parents tell about infection control?

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Introduction: Cross infection prevention has been considered very important for illness progression control. The related emotional envolvement can affect our patients' and their caregivers' life representation.
Aims: Evaluation the psychological meaning correlated to the infection control.
Methods: An interview about cross infection prevention was administered to a sample of 102 people. We administered 2 different versions: one for parents (n = 45) of CF children aged 0–11 and the other one for patients (n = 57) aged 15–49. The Eysenck Personality Questionnaire (EPQ-R) for adults or the Eysenck Personality Inventory – Junior Form (EPI) for patients aged 15–17 was administered also.
Results: We considered parents'group (PA) and patients' group (P). Some aspects have been considered very important, more important for PA than for P:
– "Having ever clean hands" (68.9%PA; 43.9%P);
– "An accurate CF Center hygiene" (95.6%PA; 86%P);
– "Disinfection of object" (75.6%PA; 19.3%P);
– "An accurate home disinfectation" (71.1%PA; 19.3%P).
We found significant negative correlations between personality scales scores and some of prevention aspects; one of them is between neuroticism score and perception of child's emotional engagement ($r = 0.309$, $p = 0.05$). Mothers have higher neuroticism scores than fathers ($P = 0.032$).
Conclusions: The results evidence that the perceived importance ascribed to prevention measures and emotional burden is less for CF patient, than in CF children patients. Moreover, fathers even if in a not statistically significant way, seem to consider more emotionally compelling for their children to stand those prevention rules than mothers do; this aspect negatively correlate with neuroticism score and mothers have higher neuroticism scores than fathers ($p = 0.032$), higher mothers' anxiety correlate with a less perception of children's emotional burden?

445 The annual assessment in cystic fibrosis; writing directly to families

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Comprehensive annual assessments are undertaken on all our patients with results being discussed with families at the next clinic visit. Previously a report was sent to the primary care physician (GP). However, recently we decided to write directly to the families (and the child if ⩾13 years), with a copy to the GP. This time consuming process had significant resource implications for the CF team. While the change in practice was initially well received, we were keen to seek the views of families and identify areas in which we could improve our communication.
Methods: Families and patients were invited to complete a service evaluation form, containing scaled options, open questions and room for free text. Children ⩾13 were encouraged to complete the form independently.
Results; 25 parents and 5 children ⩾13 years completed the form. Respondents considered the report easy to read and understand, with appropriate content. Some parents suggested other pertinent information that might also be included (for example, hearing test results and respiratory cultures). Statements regarding the report were mostly positive, with many citing how useful it was to have a written record of progress and how it helped to clarify CF treatment with other family members (particularly if they did not attend the clinic visit).
Conclusions: The annual assessment report has been positively received by our families. Early anxieties regarding the ease of understanding were unfounded. No apparent distress was caused by the report, even when evidence of declining health was contained within it. Our families were keen to have all information that was available and they value the report in its current format. This has been a successful strategy to improve communication with families.

446 "Copying letters" to CF patients: patient perceptions of benefit

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Introduction: "Copying letters" involves generating an extra copy of all correspondence between healthcare professionals about the patient, for the patient. We introduced the policy of copying outpatient clinic letters to GPs (family doctors) for CF patients in Feb 2007.
Aim: To establish patient views, perceived advantages and disadvantages on receiving the copy of GP outpatient clinic letters.
Methods: Patients who had received at least 1 copy were recruited (n = 50). Patients completed a questionnaire consisting of questions relating to their views on receiving a copy.
Results: 48/50 (96%) "Strongly agreed" or "Agreed" that key issues from clinic were addressed in the copy. 46/50 (92%) "Strongly agreed" or "Agreed" that they felt more involved in their healthcare. 44/50 (88%) "Strongly agreed" or "Agreed" that the copy helped improve knowledge. 40/50 (80%) "Strongly agreed" or "Agreed" that they understood all terms and abbreviations. Overall, 48/50 (96%) "Strongly agreed" or "Agreed" that they would rather receive a copy. 40/50 (80%) patients reported advantages including: improved knowledge 15/40; being kept informed 15/40; feeling more involved in own care 11/40; keeping their GP informed 7/40; reminder of appointments and treatments 6/40; and better explanation for themselves, friends and family 5/40. 8/50 reported disadvantages including: repeat information 3/8; complex medical terms 2/8; and privacy issues 2/8.
Conclusion: "Copying letters" was generally well received by patients and most perceived some benefits. Future evaluations should assess whether "copying letters" impacts on treatment adherence, clinic attendance and general communication with the team.